

Special Addition

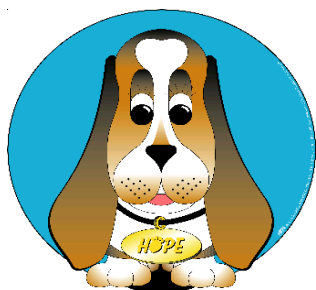


children with special health care needs

winter/spring 2006

A NEWSLETTER FOR MISSOURI FAMILIES

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Federal Viewpoint

Coping with a traumatic brain injury

by Jane Martin Heppel, Director,
Traumatic Brain Injury Program

The day after Thanksgiving 2000, Jeneesia, a high school student, was in a car struck head-on by a drunk driver. Jeneesia survived, but she wasn't unscathed. Jeneesia sustained massive damage to the right side of her body, and the frontal lobe of her brain was severely injured. Jeneesia now has challenges with pragmatic language (i.e., knowing what to say, how to say it, and to whom to say it).

Jeneesia's story is one of millions that occur each year with the same result—a traumatic brain injury (TBI). According to the Centers for Disease Control and Prevention (CDC), because of a TBI at least 5.3 million



Most traumatic brain injuries in children occur in motor vehicle crashes where the child is a pedestrian, bicyclist, or passenger. Other causes include sports-related injuries, gunshot wounds, and physical abuse such as shaken baby syndrome.



Americans need long-term or lifelong help to perform activities of daily living, such as eating, dressing, etc. The CDC's most recent statistics show

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Local Viewpoint

SHCN's assistance for head injured individuals

by Penny Goff, Special Health Care Needs

Special Health Care Needs (SHCN) has two programs to aid individuals who have

suffered a head injury.

The Adult Head Injury Program provides assistance to Missouri residents, individuals and families, in locating, coordinating, and purchasing rehabilitation and psychological services for adults who have survived a traumatic brain injury (TBI).

Individuals must be a Missouri resident and 21 years or older. Service coordination is available to adult survivors of TBI regardless of financial

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that 475,000 TBIs occur in children each year, with children under the age of four and youth between the ages of 15 and 19 the most likely to sustain a TBI. Of the 475,000, approximately 30,000 children each year are left with long-lasting, significant changes in social, behavioral, physical, and cognitive functioning that impact their ability to learn and perform in their daily lives.

Treatment difficulties

Treating a TBI can be complicated for several reasons. It is not an injury that can be seen. Unlike broken bones, a TBI cannot be mended. Additionally, it needs more than medication to heal. Further, TBI can cause a wide array of symptoms, some of which take years to appear.

Individuals with TBI may need services that cross multiple programs including comprehensive health care,

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State News Editor

Penny Goff
MO Dept. of Health and Senior Services
Special Health Care Needs
PO Box 570
Jefferson City, MO 65109
573-751-6246

State Director

Gary Harbison, MA, LPC, NCC, ACMHA,
Chief
MO Dept. of Health and Senior Services
Special Health Care Needs
PO Box 570
Jefferson City, MO 65109

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Traumatic brain injury defined

The medical definition of a traumatic brain injury (TBI) is an injury to the head from a blunt or penetrating trauma, such as a gunshot wound, or from acceleration-deceleration forces, such as motor vehicle crashes. Its severity can range from mild (a brief change in mental status or consciousness) to severe (an extended period of unconsciousness or prolonged amnesia after an injury). The Individuals with Disabilities Education Act (IDEA), the federal law that guides schools in providing special education and related services to youth with disabilities, defines TBI as "an acquired injury to the brain caused by an external, physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance."

education, vocational rehabilitation, employment, Medicaid, mental health, and substance abuse treatment. Because of a lack of coordinated systems of care, individuals with TBI are often inappropriately placed into nursing homes (regardless of their age); or are returned to their families, who frequently must provide care with little support or assistance. In some instances, individuals with TBI receive no posthospital care at all.

Another major problem is that there are individuals, many of whom are children, who have a TBI that has not been identified. Because brain injuries vary widely in their severity, changes that accompany the injury also vary. Often, children with an unidentified TBI are thought to have a learning disability, emotional disturbance, or mental retardation. As a result, they don't receive the educational help and support they need.

The Federal TBI Program

Coping with the life-changing consequences of TBI can present a great challenge for the individual with the TBI, for the family, and for the physicians, therapists, and society. For this reason, the Brain Injury Association of America, its nationwide affiliates, and numerous advocates urged the White House, Congress, and federal agencies to recognize the effects of TBI, and address the needs unique to individuals with TBI and their families.

In 1996 Congress passed the Traumatic Brain Injury (TBI) Act (the



Children with an unidentified traumatic brain injury may present new problems as they grow since they are required to use their brain in new and different ways. Damage to the brain from the earlier injury can make it hard for the child to learn new skills that come with getting older. These difficulties become more apparent when the child is in school.

only federal law that specifically addresses the issues faced by individuals with TBI) to expand studies and to build systems of care that meet individual needs in a way that is user-friendly, person-centered, and community-driven. The TBI Act created the Federal TBI Program, administered by the Maternal and Child Health Bureau of the Health Resources and Services Administration (HRSA). Until now, the Federal TBI Program had provided state agencies with money

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status. Rehabilitation services are available to individuals who are eligible for the service, and whose income is at or below 185% of Federal Poverty Guidelines.

Individuals may contact a service coordinator or, with consent, may be referred by physicians, family, friends, rehabilitation centers, service agencies, and support organizations.

The Hope Program provides assistance for children birth to age 21 who meet financial and medical eligibility guidelines. Persons ages 0 up to age 21 who have sustained a traumatic brain injury may be eligible for assistance through the Hope Program.

Participants must meet both medical and financial eligibility guidelines and reside in Missouri. Limited coverage includes outpatient tests and evaluations and/or up to five days of inpatient diagnostic evaluations. Extended coverage includes all of the above plus inpatient care, surgery, physical therapy, occupational therapy, speech and language therapy, prescription medicines, equipment, and supplies.

For more information, please call 1-800-451-0669. You will be asked to provide your county of residence and directed to the appropriate regional office for assistance.

Autism called growing problem in schools

by Bob Watson, News Tribune

Autism is a growing problem in the nation's society, and research at the University of Missouri-Columbia will help public schools better deal with affected students, members of Missouri Board of Education were told.

"There is not one thing that is autism," explained psychologist Janet E. Farmer, Ph.D., of UMC's new

Thompson Family Center for Autism and Neurodevelopmental Disorders.

"It's a set of disorders that creates a great deal of demand on family members (and others). Families often tell us heart-wrenching stories of things that don't happen for their children."

She told the board there's no one kind of autism, we don't know yet what causes it and, until we know more, there's no way of predicting when experts might find cures.

"We do know that it is a neurologically based disorder," Farmer said. "There are multiple types of children with autism disorders, and multiple causes."

As with childhood cancers, she explained, experts are trying to separate the various kinds of autism into subgroups that may be easier to understand and, therefore, easier to treat and cure.

For instance, she said, experts believe genetics may play a role in at least some of the cases.

Farmer later told reporters the "key thing (an autism diagnosis) tells you is that that child has difficulty relating to other people. That's the common theme across the different types of autism that we label these days."

In Missouri and nationally, Farmer told the board, from 1988-95 there was a 300 percent increase in the prevalence of autism cases among 5-9 year-olds.

"In general, what people are thinking is that there is a true increase in the number of children who are being identified with autism-spectrum disorders," she said.

Farmer told the board the whole field of research is hampered by a lack of long-range studies to help define the situation.

"We know this is not just a function of poor parenting," she said.

Also, experts now think that vaccines are not a likely cause, although "the press and many parents are convinced this is a factor, and we continue to study it."

Debby Parson, coordinator of Special Services for the state's Elementary and Secondary Education Department, told the board students in 346 of the state's 524 public school districts have been identified as having autism.

"We don't have an accurate count of all children within the spectrum," she said. "We only know about the ones with an IEP," or Individual Education Plan required for students with special needs.

State Board President Peter Herschend asked Farmer and Parson to recommend "policies we have or should have, to integrate with other special needs children."

He told a reporter: "We have to be able to integrate autism into the larger picture of how our special needs kids' needs are taken care of. I think everybody in this room learned a great deal about autism" from this presentation.



SHCN pandemic flu subcommittee

by Penny Goff, Special Health Care Needs

With all of the information regarding the Avian Flu in the news, several Special Health Care Needs (SHCN) staff are participating in a workgroup charged with developing a plan to assure that persons with special health care needs receiving services in the home are ready should a pandemic flu epidemic arrive in Missouri. The mission of the subcommittee is, "To ensure Missourians in the community with special health care needs are

recognized and receive full and equitable access to care.” The plan will assure that information, education, and training is made available to those providing services and/or support to the special needs population. The subcommittee also includes partnering with other state agencies and organizations associated with the care of special health care needs individuals. The plan for special health care needs individuals will eventually be incorporated into the larger state plan for all Missourians.

On February 24, 2006, Gary Harbison, Special Health Care Needs (SHCN) Chief and Jaynee Browning, Healthy Children and Youth (HCY) and Physical Disabilities Waiver (PDW) Program Manager, Co-Chairs of the SHCN Subcommittee, along with Kim Reinhardt, Health Program Representative II and Penny Goff, Health Program Representative II attended the Missouri Pandemic Flu Summit in St. Louis, MO. Governor Matt Blunt and several other notable speakers presented information regarding a course of action for Missouri to prepare for a pandemic flu epidemic.

The workgroup meets monthly by conference call and holds face-to-face meetings quarterly. A finalized statewide plan is anticipated by May 2006.

Hazardous look-a-likes in a child's world

by Karma Metzgar, C.F.C.S., Former Northwest Region Regional Nutrition Specialist
Nodaway County Extension Center, University Outreach and Extension
Updated by Gail Carlson, MU Health Education Specialist - 3/7/03
Updated by Greta Hopke, RD and Candance Gabel, MS, RD, LD, Associate State Nutrition Specialist University of Missouri Extension - 3/8/05

Young children are known to be very curious and active. Can you think of the last time you

were with a kid and you turned your back or went into another room to return in just 2 minutes to find the child was somewhere else? Young children love to imitate, explore, and try new things. While this is a great way for them to learn, this curious instinct can be very dangerous in the wrong situation.

“Children Act Fast, So Do Poisons!” was the theme of National Poison Prevention Week, March 20 to 26. This is a special week designated to increase awareness of the dangers of accidental poisoning. According to the Poison Prevention Week Council, approximately 1 million phone calls are placed each year to the Poison Control Centers by adults seeking help when a child has swallowed or come into contact with a harmful substance with about 30 of these children dying each year.

Kids connect color, shapes, texture, and flavors with foods. Whether it is medicine or scented crayons or markers, it can be difficult for them to separate safe from unsafe when it smells like food. Take a look in your cleaning supplies for “food scented” items. No, they are not to eat, but are pleasant to smell and very similar to the smell of some foods.

There are numerous poison look-a-likes in our homes. If the label from the product were removed and put into containers, could you pick out what was safe and what was not? Just think about some of these poison look-a-likes:

- Cinnamon red hots and cold medicine
- Water and alcohol
- Candy and antacid
- Cake frosting in a tube and first aid cream
- Vitamins and cake decorations
- Dishwashing soap granules and Nerds® candy
- Tuna and cat food
- Jelly and sunscreen
- Lettuce and spinach and some green house plants

■ Corn oil and dish soap
As you can see, this is a fairly common list of things we keep in our kitchens, bathrooms and cleaning closets. Move to a garage, farm machine shed, or storage area and you'll likely discover other poison look-a-likes.

To poison proof, move containers out of sight to high shelves or closets, away from foods where they might be mistaken for a “safe” food. Medicines can be put into larger containers on a high shelf. If possible, keep these products in a locked cabinet. Also, keep items in their original containers with the label on. Children associate cups, bottles, or other containers with food and drink and it can be confusing to all of us if they are not in the original container!

When taking medicine or nutritional supplements it is important to follow the directions presented on the label. Never refer to medicine or supplements as “candy.”

When using a cleaning product, always follow the directions on the label and keep the child and product in your sight. When reading the label, look for these key words: CAUTION or WARNING, this indicates a mild hazard. In event of accidental exposure, if appropriate first aid is given, the product will not likely cause permanent damage. Most detergents, disinfectants, and all-purpose cleaners fit into this category.

DANGER indicates that a greater precaution should be taken. In the event of accidental exposure, this product could cause long-term damage. Products with this keyword typically are intended for tough jobs, such as oven cleaners, drain openers, or products which are flammable.

POISON is the strongest indication of hazard. In the event of accidental exposure, this product could cause severe medical damages. This term rarely appears on household cleaning products, but may be found on car care products and anti-freeze.

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When we think of kids and poison, we often imagine the child swallowing the item, however, smelling or touching a substance can also be harmful. In case of a poison accident, keep the Poison Control Center number posted in the phonebook or on the refrigerator. The number, **1-800-222-1222**, provides everyone in the U.S. with free access - 24 hours a day, 7 days a week - to their regional poison center. When calling the Poison Control Center, be sure to have the following information: the child's age and weight, any health or medical conditions, the substance involved, whether they smelled, swallowed, or touched the product, if any first aid has been given, and if the child has vomited.

To keep "quick" and curious kids safe, become a kid again. Get down on your hands and knees. What can you find or get into? Are there things that need to be moved? If so, do it now and keep the kids safe.

For more information see: <http://missourifamilies.org/features/healtharticles/health15.htm>



Like me

by Emily Perl Kingsley

*I went to my dad and said to him,
There's a new kid who's come to my school.
He's different from me and he isn't too cool.
No, he's nothing at all like me, like me,
No, he's nothing at all like me.*

*He runs in a funnyish jerkyish way
And he never comes first in a race.
Sometimes he forgets which way is first base,
And he's nothing at all like me, like me,
No, he's nothing at all like me.*

*He studies all day in a separate class
And they say that it's called "Special Ed."
And sometimes I don't understand what he's said,
And he's nothing at all like me, like me,
No, he's nothing at all like me.*

*His face looks kind of different from mine,
And his talking is sometimes so slow
And it makes me feel funny and there's one thing I know;
He's nothing at all like me, like me,
No, he's nothing at all like me!*

*And my father said, Son, I want you to think
When you meet someone different and new
That he may seem a little bit strange, it's true,
But he's not very different from you, from you,
No, he's not very different from you.*

*Well I guess, I admitted, I've looked at his face;
When he's left out of games, he feels bad.
And when other kids tease him, I can see he's so sad.
I guess that's not so different from me, from me,
No, that's not very different from me.*

*And when we're in Music, he sure loves to sing,
And he sings just like me, right out loud.
When he gets his report card, I can tell he feels proud,
And that's not very different from me, from me,
No, that's not very different from me.*

*And I know in the lunchroom he has lots of fun;
He loves hot dogs and ice cream and fries.*

*And he hates to eat spinach and that's not a surprise,
'Cause that's not very different from me, from me,
No, that's not very different from me.*

*And he's always friendly, he always says hi,
And he waves and he calls out my name.
And he'd like to be friends and get into a game,
Which is not very different from me, from me,
No, I guess that's not different from me.*

*And his folks really love him, I saw them at school,
I remember on Open School Night --
They were smiling and proud and they hugged him real tight,
And that's not very different from me, from me,
No, that's not very different from me.*

*So I said to my dad, Hey you know that new kid?
Well, I've really been thinking a lot.
Some things are different...and some things are not...
But mostly he's really like me, like me,
Yes, my new friend's...a lot...like me.*



Help your child snack smart

by Rita Arni, RD, LD
WIC and Nutrition Services

Most kids like snacks. That's great! Think of snacks as mini-meals that help provide nutrients and food energy your child needs to grow, play and learn.

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Help your child snack smart. Your child has a small stomach. So he or she probably eats less at meals than you do. Smart snacks can help your child eat and drink enough during the day. In fact, most young children do best when they eat four to six times a day.

- Let snacks fill the gaps. If your child misses juice for breakfast, offer fruit at snack time. If your child has low iron stores, offer snacks high in iron.
- Time snacks carefully. Serve snacks two to three hours before meals. That way your child will be hungry for lunch or supper.
- Offer snacks to satisfy hunger. Skip the urge to offer a snack to quiet tears, calm your child, or reward behavior. That can lead to emotional overeating later on.
- Keep snacks small. If your child is still hungry, he or she can ask for more. Let your child decide what is enough.
- Snack wisely yourself! Do you snack when you feel stressed or bored? What foods do you snack on? Remember, your child learns snack habits by watching you. Be a great role model!

- Go easy on snacks with added sugars. Offer milk, juice, or water as drinks with the snack. Soft drinks, fruit drinks and sports drinks can crowd out foods your child needs to grow and stay healthy.
- Make foods from the food groups as the usual snacks. A little candy occasionally is okay. Offer snacks from the food groups, such as raw vegetables, fruit, milk, cheese, yogurt, bread, whole-grain cereals, peanut butter and hard-cooked eggs most of the time.
- Sometimes kids say they're hungry when they really want attention. Take a little time with your child. Talk or do something fun. Your child will let you know if he or she really is hungry.

Quick snacks to keep on hand include:

- Whole fruit, sliced into finger foods
- Berries
- Raw, cut up vegetables
- Graham crackers
- String cheese
- Cheese and crackers
- Bagel and peanut butter
- Yogurt topped with granola

- Whole-grain cereals (Look for cereals with no more than 35% added sugars by weight, or about 8 grams of sugar per serving)
- Rice cakes
- Tuna

Easy-to-make snacks include:

- Crunchy banana: Peel bananas. Roll them in peanut butter or yogurt, then crushed cereal. Freeze!
- Cinnamon toast: Toast whole wheat bread. Spread a little margarine on top. Sprinkle with cinnamon sugar.
- Cheese Quesadilla: Sprinkle grated cheese on a flour tortilla. Microwave just until cheese is melted. Roll up.
- Fruit smoothie: Blend fruit with juice, yogurt or milk, and ice. Many store-made smoothies have added sugars and are not healthy choices, so make your own!

For more smart snacking ideas, go to http://www.cspinet.org/nutritionpolicy/healthy_school_snacks.pdf.

What are your child's favorite snacks? Make a list and keep on hand for grocery shopping, snack time, and to share with childcare providers.

My Favorite Snacks	
Child's Name:	
Green fruit	
Green vegetable	
Yellow fruit	
Yellow vegetable	
Orange fruit	
Orange vegetable	
Red fruit	
Red vegetable	
Blue/Purple fruit	
Blue/Purple vegetable	
White fruit	
White vegetable	
Cereal	
Bread or Grain	
Low-fat milk product	
Nuts	
Meat and Beans	
Beverage	
Other favorite snacks	

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via grants to care for individuals with TBI and their families. This year the Federal TBI Program created a new grant category for state agencies, the Partnership Implementation Grant, which will take the place of the other grants. The new implementation grants will allow states and territories to expand and improve their statewide and local resources devoted to TBI. The goal of the Federal TBI Program is to have all individuals with TBI and their families obtain accessible, available, acceptable, and appropriate services and supports.

State agency grant accomplishments

Since 1997, 48 states, two territories, and the District of Columbia have received at least one TBI grant. States have used the planning grants to build systems of care where an individual can access a "seamless" system of services—meaning that an individual and his or her family can easily move from one setting within the system to another. For example, if a toddler is hospitalized from a playground injury and a TBI is diagnosed, the child's family can count on the transfer of services from the hospital to the child's pediatrician.

Jeneesia is one of the beneficiaries of the Federal TBI Program's state agency grants.

As an Alabama resident, she was directed to the Alabama Children's Rehabilitation Services.

Because of her injuries, Jeneesia had to relearn how to speak, and she still struggles with language difficulties.

After working with educators and others, she is currently plotting her career map by working with a vocational rehabilitation counselor. The three-year TBI Implementation grant enabled the Alabama children's program to expand its services to

more than 518 children with TBI.

When students go back to school after sustaining a TBI, many teachers may be aware of the unique challenges these students present, but are not prepared or trained to meet their needs. In response to this, Iowa, Kansas, and Oregon developed a model called the TBI Resource Team Model in which team members (family members, individuals with TBI, school nurses, and others) are recruited and trained to be knowledgeable about issues related to TBI. In addition, training and direct consultation is given to teachers who have a student with a TBI. A webcast discussing the model is available online (see box at left on page 8).

Parents of students with TBI applaud the states' efforts because they've found the TBI Resource Team Model meets their children's needs. One father praised the model after regional team specialists helped

develop an Individual Education Plan (IEP) tailored to his child's unique needs and changed learning style. An IEP is one of many strategies that can

be used to help children continue to learn effectively after a TBI. Parents have also praised the TBI Resource Team Model for its help in establishing camaraderie among people who have a TBI, or who have an interest in helping those with TBI.



Protection & Advocacy grant successes

With the Children's Health Act of 2000, Congress created a mechanism for the Federal TBI Program to also provide grants to Protection and Advocacy (P&A) services. Its purpose is to ensure that P&A services could provide assistance to individuals with TBI and their families, regarding their rights related to education, employment, housing, transportation,

and other issues. Sometimes P&A services only provide correct information and a referral to the correct helping agency. In other instances, it is necessary to engage in litigation to support the rights of an individual or group of individuals with TBI.

Just as adults with TBI may need protection or advocacy to get their needs met, children and youth also have an array of advocacy needs related to providing a supportive learning environment, or to getting needed assistive technology (see box at right on page 8), or ensuring that public places such as libraries are accessible. Protection and Advocacy services can encourage needed changes in making facilities acceptable to those with a TBI, just by making some phone calls and advising others of what the law provides for persons with a disability such as a TBI. In some instances, children and teenagers have been inappropriately placed in facilities designed primarily for the aged and infirm. The P&A services have fought to have these young people released from such institutions, so that they can receive the necessary services and supports they need within their own home and

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~Everyone involved in the acute aftermath of a TBI feels stressed and bewildered as to how to cope with an event that can change life forever.~



Families and individuals with traumatic brain injury (TBI) need a well-traveled path for them to follow, one that is peopled with other individuals with TBI and their families who can offer friendly support and comfort. One that has everything that will be needed, conveniently located with well-marked signs to guide them on their journey.

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community.

The HRSA P&A grants have allowed 57 states, territories, and the Native American Protection and Advocacy Project to assess their state P&A systems' responsiveness to TBI issues and provide advocacy support to individuals with TBI and their families. Although all protection and advocacy cases are compelling, one P&A advocate said, "Cases involving children and youth bring great satis-

faction since they [children and youth] are much more vulnerable than adults."

The road ahead

A TBI is just that—traumatic for both the survivor and the family. Everyone involved in the acute aftermath of a TBI feels stressed and bewildered as to how to cope with an event that can change life forever. It is especially painful for parents who have invested their hopes in a child who is now injured in ways that will unfold over a period of months to years. They fear for their child's possibly unrealizable potential, and for their suddenly magnified responsibilities.

With continued authorization and appropriations from Congress, the HRSA TBI programs will be able to help more individuals with TBI, like Jeneesia and Brian (see box at right), and their families. Just as important, because of these programs, the public will have a heightened awareness of TBI, which could ultimately result in measurable progress in TBI prevention.

A success story

One young person who would not have had a proper education had it not been for the existence of the Protection and Advocacy (P&A) grant is Brian, an eleventh grader from Tennessee. Brian has both a TBI and quadriplegia and uses a wheelchair. Brian's father contacted the Tennessee P&A services because the school was not allowing the use of a communication device (the Dynavox), which was part of Brian's Individual Education Plan (IEP). The school had refused to send staff to free trainings on how to use the equipment. The Tennessee P&A services convinced the school to allow Brian to use the Dynavox, and to obtain the necessary training on how to use it. Brian also received further assistive technology and occupational, speech, behavioral, and cognitive evaluations. He was able to begin the 2004-2005 school year with all services and supports in place and, therefore, have an increased amount of independence.

A webcast discussing the TBI Resource Team Model is available online at: <http://www.mchcom.com/archivedWebcastDetailNewInterface.asp?aeid=335>

Missouri Department of Health and Senior Services
Special Health Care Needs
PO Box 570
Jefferson City, MO 65109

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